Privacy Policy

The LHON Collective takes very seriously the privacy of its website visitors and the security of any personal information that may be provided via the organization's website. The LHON Collective believes you have the right to know the type of information the organization collects, how it is protected and used, and the circumstances under which it may be disclosed.

Any privacy policy provided on any specific LHON Collective-branded website will always supersede this general policy. Please check the LHON Collective website(s) that you use for the applicable privacy policy.

The Information We Collect and How it is Gathered and Used

Personal Information

This notice applies to all information collected or submitted on the LHON Collective website. On some pages, visitors can make information requests, register to receive program updates or resource materials, or make financial contributions. The LHON Collective collects only the personal information voluntarily provided through this website. This may include, but is not limited to, your name, email address, contact information, credit card information and any other demographic data or details related to your background or interests that you choose to provide.

The LHON Collective does not share personal information provided by you through its website with any other institution, company, government or governmental agency or other organization. The LHON Collective is obligated to disclose personal information in exceptional cases as required by US law, including a subpoena.

The LHON Collective uses the information you provide about yourself for various services, which are disclosed to you when you provide the information. Examples include email newsletters, invitations to LHON Collective events, or for information alerts about LHON Collective programs or activities. In some cases, the LHON Collective uses this information, including the email addresses and contact information gathered from our websites, for fundraising activities.

Information collected on the LHON Collective website are never used for commercial purposes.

Site Usage Information

When visitors browse, read or download information on the LHON Collective website, limited, anonymous data is collected about the visit. For instance, the web server may record the numerical Internet Protocol address of your computer; information about your browser and operating system; date and time of access; and the Internet address and page that linked (referred) you to our site. If you search the site, your search requests may be logged. The LHON Collective uses this information to measure the number of visitors to different sections of the site, diagnose and correct system errors, and conduct research—all with the sole objective of improving the information services, features and usability of the site.

Cookies

The LHON Collective uses cookies to distinguish you from other users on its website. Doing so helps us improve our website and provide you with a good experience. However, cookies have received criticism because parties can also employ them to invisibly assemble information about a user's browsing habits for marketing purposes. The LHON Collective uses cookies only to improve the user experience within the context of a single browser session or between website visits, and not for any form of information gathering about user browsing. Persistent cookies remain on your personal computer or mobile device when you go offline, while session cookies are deleted as soon as you close your web browser. The LHON Collective use both for the following purposes:

Necessary / Essential Cookies

Type: Session Cookies Administered by: Us

Purpose: These are cookies that are required for the operation of our website. They

help to authenticate users and prevent fraudulent use of user accounts.

Functionality Cookies

Type: Persistent Cookies Administered by: Us

Purpose: These cookies allow us to remember choices you make when you use our website. The purpose of these cookies is to provide You with a more personal experience and to avoid you having to re-enter your preferences.

Tracking and Performance Cookies

Type: Persistent Cookies

Administered by: Third-Parties

Purpose: These cookies track information about traffic to the website and indicate how visitors use the site. The information gathered may directly or indirectly identify you as an individual visitor. This identification typically results from the collection of information typically linked to a pseudonymous identifier associated with the accessing.

Targeting and Advertising Cookies

Type: Persistent Cookies

Administered by: Third-Parties

Purpose: These cookies track your browsing habits to show advertisers content likely to interest you. These cookies use information about your browsing history to group you with other users possessing similar interests. Based on that information, and with our permission, third party advertisers can place cookies that enable them to suggest third party websites based on those interests.

Social Media Cookies

Type: Persistent Cookies

Administered by: Third-Parties

Purpose: We may also use various third party plug-ins from social media networking websites such as Facebook, Twitter, or LinkedIn to report usage statistics of the Website and to provide social media features. These third-party plug-ins may store Cookies. We do not control these Social Media Cookies. For more information, please refer to the relevant social media networking's website privacy policies.

Every user will be given the opportunity, via a cookie banner, to refuse or withdraw their consent when visiting the LHON Collective website. However, the refusal of certain cookies may prevent the full functionality and/or create some inconveniencies when using our website.

The LHON Collective Commitment to Data Security

To prevent unauthorized access, maintain data accuracy and ensure the correct use of information, The LHON Collective uses industry standard SSL (Secure Sockets Layer) encryption to protect the confidentiality of your personal information and the security of your transaction during transmission.

Overview and Donor Access Rights

The LHON COLLECTIVE appreciates those individuals and entities whose contributions finance the LHON COLLECTIVE's operations ("Donors"). To that end it wishes to explicitly clarify the types of Donor Information it receives, and its procedures with respect to this information.

Further, in addition to other safeguards listed in this privacy policy, the LHON COLLECTIVE confirms that (unless required to comply with law, statute, or regulation) it does not sell or share a Donor's Personal Data without its explicit consent. A Donor that has provided such consent may revoke such consent at any time via written notice and, subject to exceptions stated in applicable law, the LHON COLLECTIVE shall act in accordance with such revocation. For avoidance of doubt, this addendum applies equally to Donor Personal Data received through this website and any other forms of information acquisition.

Any revocation of consent may be submitted to the following email address: mmarsh@lhon.org

With respect to offline donations:

- The LHON COLLECTIVE staff may obtain basic personal data including address, email, and phone number. Incidental to the form of payment, the staff involved with donation in the form of a physical intake may have access to information located on a check. Such physical checks will be discarded upon either (a) physical cashing of the check, or (b) in line with the recommendations provided by the LHON COLLECTIVE's bank's mobile application.
- 2. Offline potential donors may prefer to provide credit card information. Staff will not solicit such information, and shall inform the donor of other payment options, prior to accepting this information.
- 3. Staff responsible for finance and accounting may have access to such information provided by Donors as necessary for financial accounting of donations in line with generally accepted practices.
- 4. Basic personal data and donation amounts may be uploaded into databases utilized to document the donor-organization relationship.
- The LHON COLLECTIVE will periodically review personnel, or categories of personnel, having access to the information described in points (1)–(4). It will periodically refine access rights, limiting access to those reasonably having a need to know. Accounts having such access will be password protected.
- 6. The LHON COLLECTIVE may utilize third party software and vendors in connection with this process. It shall periodically review such vendors to

- verify their privacy practices, and commitment to processing data in line with best practice (including the use of encryption technologies) and applicable the LHON COLLECTIVE's policies.
- 7. The LHON COLLECTIVE will retain such Donor Information in line with its Data Retention Policies.

With respect to online/digital donations:

- Payments are processed through third party sites and vendors, and monitored by Communications and Finance Staff. The LHON COLLECTIVE collects basic information (such as name, email, and other information that Donor elects to provide), and the amounts paid. Encrypted information and partial credit card information may be transmitted from such providers to verify payment.
- 2. Staff responsible for finance and accounting may have access to such information as necessary for financial accounting of donations in line with generally accepted practices.
- 3. Basic personal data may be uploaded and stored into databases utilized to document the donor-organization relationship.
- 4. The LHON COLLECTIVE will periodically review personnel, or categories of personnel, having access to the information described in points (1)–(3). It will periodically reevaluate access rights, limiting access to those reasonably having a need to know. Accounts having such access will be password protected.
- 5. The LHON COLLECTIVE may utilize third party software and vendors in connection with this process. It shall periodically review such vendors to verify their privacy practices (including the use of encryption technologies), and commitment to processing data in line with best practice and applicable the LHON COLLECTIVE's policies.
- 6. THE LHON COLLECTIVE will retain such Donor Information in line with its Data Retention Policies.

Data Subject Rights and Requests

You have rights when it comes to how we handle your personal data. These rights vary depending on where you reside, but may include rights to:

- Transfer or access personal data
- Correct personal data
- Erase personal data
- Object to the processing of personal data

• Withdraw consent to further processing of personal data

A LHON Collective representative will respond to your request in a timely manner, and in no event longer than 30 days. To initiative this process, you will be required to submit this <u>Data Subject Access Request Form</u>. Should you have additional questions or concerns, please contact our Data Protection Unit at <u>mmarsh@lhon.org</u>.

Changes to this Policy

The LHON Collective retains the right to make changes, at its sole discretion, to this Privacy Policy Statement or the privacy policies of its various program websites, which will be posted in an accessible place on the pertinent site.

How to Contact the LHON Collective

Should you have other questions or concerns about these privacy policies, please send us an email at mmarsh@lhon.org.